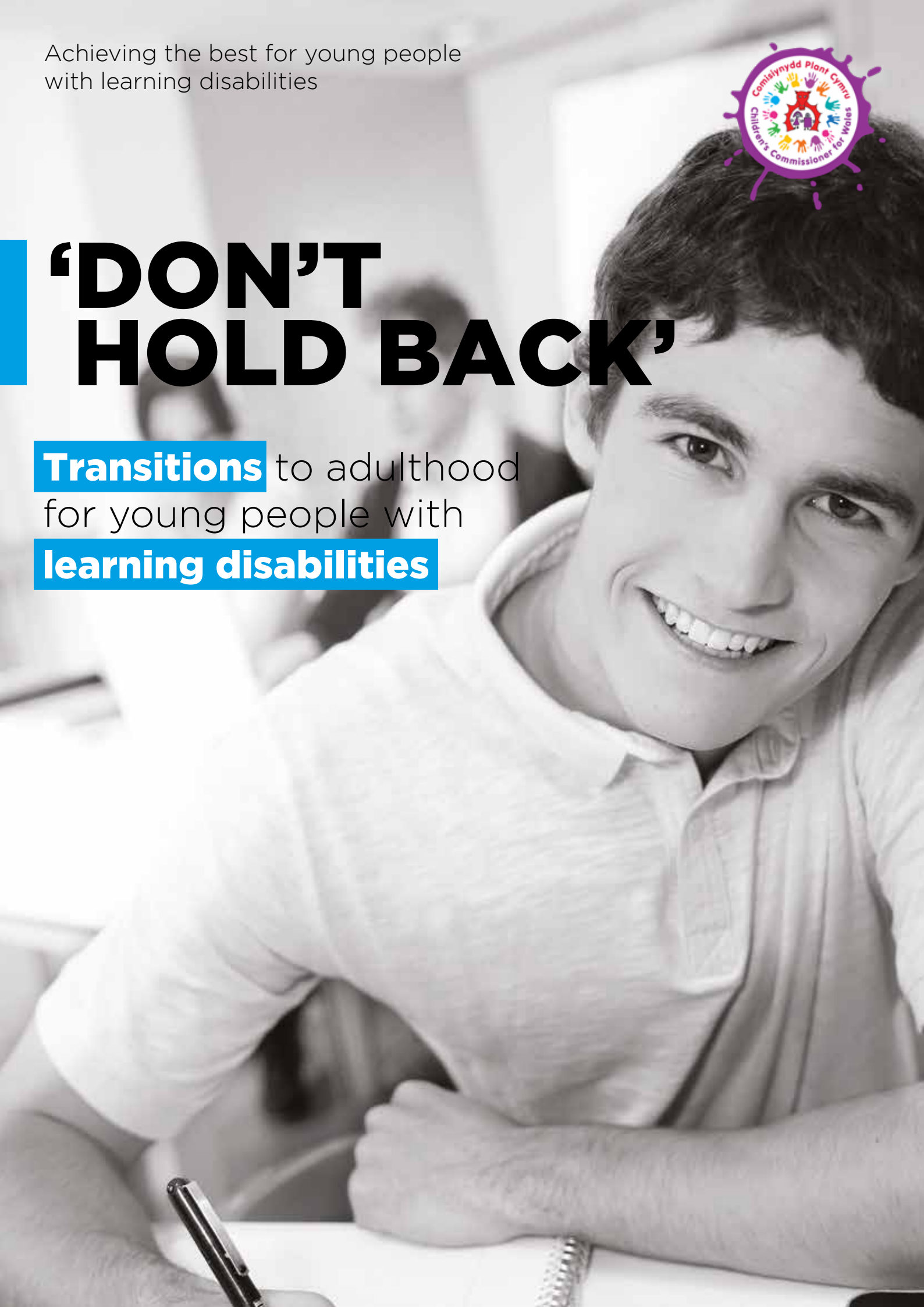


Achieving the best for young people
with learning disabilities



'DON'T HOLD BACK'

Transitions to adulthood
for young people with
learning disabilities



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DON'T HOLD BACK

Foreword by Sally Holland, Children's Commissioner for Wales

This report began with one conversation. It was in November 2016, when I had a long discussion with the parents of young people with learning disabilities and complex needs in a support group in north Wales. At the end of the discussion I asked each one of them what they would do if they had a magic wand.

One mother said, "For my daughter never to grow up. I know it sounds terrible, but I have struggled so hard to get her the education and support she needs, and I have no idea how she will be supported when she's an adult." It was an answer that stuck with me, and troubled me.

The human rights of children and young people with learning disabilities are protected by the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In Wales we have some important legislation that recognises these rights and requires services to be centred around each person's needs, to involve people in planning their own care, to be preventative and to be integrated. These Acts, the Social Services and Well-being (Wales) Act 2014 and the Well-being of Future Generations (Wales) Act 2015, were established to address the very real battles and concerns raised by that North Wales-based mother, and many thousands like her across Wales. But clearly these Acts are failing to deliver the support needed for young people with learning disabilities as they move towards adulthood.

This report brings the experience and views of **99 young people, 187 parents and carers, and 43 professionals**, which reflect the need for government and public services to take concerted action to make sure that the positive aims of those

two pieces of legislation translate to the standards of service and support that young people with learning disabilities have a right to.

All young people need support as they move towards adulthood. Young people with learning disabilities have the same hopes for a good adult life but most will need additional help. The services that their families may have worked so hard to get for them will usually change when they reach the age of 18 (although the age differs in different services). There is almost universally a huge task for young people and their families to navigate and negotiate the move to adult health and social services, college courses and the prospects of employment or other worthwhile activity after college.

In this report we hear from a few families that have been well supported through this period, with dedicated transitions support, including life skills development from local authority or voluntary sector projects. However, the majority have found this process confusing, difficult and anxiety provoking. Young people have not had the opportunities to be involved in this planning that they have the right to, with planning too often done 'about them' rather than 'with' them.

Further integration of services is hard, but will reap enormous benefits for the experiences of children and young people with learning disabilities and

their families. It will also be more effective and efficient. It makes no sense to have a system so incoherent that we need to employ special workers to help families navigate them. But this form of key worker support will continue to be desperately needed until the system itself can be made much smoother.

And, finally, we should be aspiring to much more than smoother systems and processes. At heart here is the need to ensure that people with learning disabilities are able to take their place

as full and active citizens. This period from the mid-teens to the mid-twenties is a crucial window to ensure that young people are fully equipped and supported for life. We need to have much greater expectations that as a society we are prepared to find ways to reduce the stigma and social exclusion of disability and welcome children and young people with learning disabilities as equal citizens in our schools, workplaces and communities.

Key messages

from young people and their families:

- **Young people's participation** in planning and decision-making appears to be very low – this means that their different priorities and specific interests can get missed.
- **Parents play a crucial role** and are relied upon to do so, but often feel overwhelmed and anxious about the future – they need support and recognition.
- **Some young people face** a considerable change in how much support they receive after the age of 18 due to different thresholds rather than a sudden change in need – contrary to the Social Services and Well-being (Wales) Act 2014.
- **Every service has different ways** of transferring to over-18s services. Having a key worker or transition service is very valuable.
- **Social isolation is a problem** for many – even though friendships are rated as young people's top priority.
- **There are very limited opportunities** for work and apprenticeships, with no supported employment opportunities – despite evidence suggesting this is particularly effective.
- **Young people, parents and professionals** all agree that young people with learning disabilities are still expected to slot into services that already exist, with limited options if that doesn't fit their needs.
- **Almost all of the above points run contrary to the aspirations of the Social Services and Well-being (Wales) Act 2014 and the Well-being of Future Generations (Wales) Act 2015, and to rights under the UNCRC and UNCRPD.**
- **Where young people and their families** reported good experiences, they had been involved, they were clear about the process, they felt well supported by a keyworker, lead professional or dedicated transitions service and they often had access to a youth-centred provision that helped young people prepare for adulthood and expand their social and community networks.

INTRODUCTION

All children's rights under the UNCRC are equal and applicable to all children. However, the convention itself recognises the vulnerability of disabled children providing not only a reminder that they should live as full as lives as possible but a requirement for 'government to do all they can to support disabled children and their families.'²

This report comes at a point in time when there are significant changes and developments taking place in Wales which will affect the lives of children and young people with learning disabilities and their transition to adulthood. These changes include but are not limited to; the development of Additional Learning Needs regulations and mandatory Code, the review of the children and young people's Continuing Care guidance, developments in work programmes under the 'Prosperity for All: Employability Plan', and the work programmes of the still relatively new Public Services Boards and Regional Partnership Boards. Many of these are referenced within the Government's Improving Lives Programme - which specifically provides recommendations for improving outcomes, in respect of people with learning disabilities - and have the potential to have a positive impact on people with learning disabilities in Wales across what is described as their "life span."

In light of all of these developments, this juncture is an opportunity for Welsh Government, statutory partners and others to pay specific attention to how they can improve the lives of children and young people in Wales including those with learning disabilities approaching adulthood.

In this report I make a number of recommendations related to established legislation, namely the Social Services and Well-being (Wales) Act 2014, but also about the forthcoming developments identified above.

LEARNING DISABILITY

Definition of learning disability:

The charity MENCAP provides a full explanation:

- **A learning disability** is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.
- **People with a learning disability** tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.
- **The level of support someone needs** depends on the individual. For example, someone with a mild learning disability may only need support with things like getting a job. However, someone with a severe or profound learning disability may need fulltime care and support with every aspect of their life – they may also have physical disabilities.
- **People with certain specific conditions** can have a learning disability too. For example, people with Down's syndrome and some people with autism have a learning disability.
- **It's important to remember** that with the right support, most people with a learning disability in the UK can lead independent lives.¹³

Children with learning disabilities in Wales

How many children in Wales have learning disabilities?

A cross party report in respect of people with learning disabilities recognises that “data on people with a learning disability are recognised as being poor in Wales.”⁴

Mencap estimate that approximately 193,707 school age children have a learning disability in the UK. This would suggest that around 9,297 children in Wales have a learning disability. The extent to which this impacts on their everyday lives will be very varied. Around half of that number, 4,727 are in special school. Many but not all pupils in those schools will have a learning disability. Very many other children with a learning disability are being supported to attend mainstream schools.

POLICY CONTEXT AND LEGISLATION

Social Services

The Social Services and Well-being (Wales) Act 2014 came into force on 6 April 2016. The Explanatory Memorandum produced when the Bill was introduced to the National Assembly for Wales states the following on page 4:

“The Social Services and Well-being (Wales) Bill provides for a single Act for Wales that brings together local authorities’ duties and functions in relation to improving the well-being of people who need care and support and carers who need support. The Bill provides the statutory framework to deliver the Welsh Government’s commitment to integrate social services to support people of all ages, and support people as part of families and communities.

“It will transform the way social services are delivered, primarily through promoting people’s independence to give them stronger voice and control. Integration and simplification of the law for people will also provide greater consistency and clarity to people who use social services, their carers, local authority staff and their partner organisations, the courts and the judiciary. The Bill will promote equality, improve the quality of services and the provision of information people receive, as well as ensuring the right incentives for commissioners to achieve a shared focus on prevention and early intervention.”⁵

The Act introduced some new provisions such as an automatic entitlement for carers to have an assessment of their own needs independent of the needs of the person they care for, and new structures such as Regional Partnership Boards that bring together local authorities, health boards and other agencies including third sector representatives, to assess and plan how to meet the needs of the population in their area. The Act is due to be formally evaluated by the Welsh Government to monitor the impact that it has had since it was introduced.

Under the Act, the Part 9 Statutory Guidance (Partnership Arrangements) makes it clear that Regional Partnership Boards (RPBs) identify priority areas for support, including people with learning disabilities and children with complex needs due to disability or illness. RPBs are required to integrate services in relation to people with learning disabilities, children with complex needs due to disability and transition arrangements from children to adult services.

The Partnership Arrangements Regulations require RPBs to prepare annual reports on the extent to which the board’s objectives have been achieved, and submit these to Welsh Ministers.

These reports should specifically set out the steps taken to integrate services as noted above, and if not yet progressed, the steps that will be taken in the following year in order to achieve this.

Education

The Additional Learning Needs and Education Tribunal (Wales) Act 2018 received Royal Assent in January 2018. The Act introduces the definition of Additional Learning Needs and creates a single legislative framework for learners from 0-25. The Act will be supported by regulations and a code which will include statutory guidance and mandatory requirements. These are in the first phase of development. The Welsh Government has said that the practical implementation of the Act is due to start in 2020 and be completed in full by 2023. In the meantime the Education Act 1996, the relevant regulations in respect of Special Educational Needs and the 2004 SEN Codes of Practice remain in place. The Code of Practice provides the detail in respect of current transition planning which should start at the child’s review in year 9 (the mid point in secondary school).



Equality Act 2010

The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. It replaced previous anti-discrimination laws with a single Act, making the law easier to understand and strengthening protection in some situations. It sets out the different ways in which it's unlawful to treat someone.⁶ It includes the public sector equality duty - "the broad purpose of the equality duty is to integrate consideration of equality and good relations into the day-to-day business of public authorities."⁷

The Well-being of Future Generations (Wales) Act 2015

The Well-being of Future Generations (Wales) Act 2015 established new Public Services Boards (PSBs), which bring together senior leaders from health, social services, police and fire services, Natural Resources Wales and voluntary organisations. Each PSB is required to publish a Local Assessment of Well-being, to set out the state of economic, social, environmental and cultural well-being in that PSB area.

Public bodies in Wales, as named in the Act, are required to evidence that their work fits with the five ways of working; long term, prevention, integration, collaboration and involvement.

Health and Social Care Act 2008

"Health and social care organisations have to make "reasonable adjustments" in how services are provided in order to reduce preventable inequalities in health by people with a learning disability."⁸

Policies

In 2017, the Welsh Government commissioned a Parliamentary Review of Health and Social Care. The final report entitled "*A Revolution from Within: Transforming Health and Care in Wales*"⁹ was published in January 2018 and the Welsh Government has recently set out its vision for "*A Healthier Wales*" in response to this.

The Welsh Government's vision and aims for the current Assembly Term are included within their strategy document "*Prosperity for All*." This is "a single cross-cutting strategy to inform all decision-making and to provide a framework for improved cross-governmental working and to improve the quality of people's lives."¹⁰

In 2007, a statement of policy and practice for people with learning disabilities was published. These are: "the most recent guidance document and still relevant today" according to the Minister, but a review of services was needed to bring everything up to date in light of legislative changes. The resulting programme, "*The Learning Disability - Improving Lives Programme*" is a separate cross-government review of learning disability services, which was completed by the Welsh Government in March 2018. A Cabinet Paper about the review states that:

"Prosperity for All and the Parliamentary Review present clear opportunities to take forward the recommendations."¹¹

The timing of this report therefore coincides with significant opportunities to change the way that health and social care services are being provided in Wales, to ensure that person centred planning and provision are at the centre. Listening to the voices of particular vulnerable groups such as children and young people with additional needs that are likely to continue into adulthood are extremely important to the success of any changes that are made as a result of these recent reviews.

WHAT WE DID

We recognised that there were others who already had a lot of specialist knowledge in this area. We therefore arranged for two teams to do the research work that provided the content for this report.

There were two elements to this:

a) A review of the evidence: what is already known from research?

Dr Axel Kaehne and his colleagues in Edge Hill University conducted a 'rapid review' of existing research into this topic. On our request they looked particularly at the relevance of research to Wales. Out of nearly 3000 research papers close to this subject, they found 58 that were particularly relevant. Their analysis of these 58 research studies is referred to throughout this report. The full evidence review can be found [here](#). In this report, you will see findings from the rapid review report in separate blue boxes, like this:

Our evidence review of other research studies found:

b) The direct views and experiences of young people, their parents or carers and professionals

Most of the evidence in this report comes directly from young people with learning disabilities and the adults who care for them or work with them. We engaged Vikki Butler and her team at CARP Collaborations to do this work. They worked in partnership with a **peer researcher** – a young researcher with learning disabilities – to help them get this right.

They listened to the views of:

- **99 young people aged 14-26** – in 10 face to face focus groups and one Skype session
- **187 parents** of children and young people with learning disabilities, nearly all aged 14-25 – in an online questionnaire
- **43 professionals** from education, social care, health and voluntary services in focus groups
- **6 national voluntary organisations** through written submissions.

Although all participants were self-selected (or chosen by their school or college to take part) they represent very varied experiences. There were young people involved from most areas of Wales, although the rural areas of mid and west Wales are over-represented in the sample compared to the general population. 17% of the young people spoke Welsh (with another quarter speaking some Welsh). This is 2% lower than the general population. 5% were from a Black or Minority Ethnic background, which is similar to the population in Wales. Young people's participation took place through focus groups that were adapted to their needs, but some young people with the most severe learning disabilities did not take part. However, some of their experiences are represented by parents and professionals.

FINDINGS



This report takes the perspectives of young people, their families and professionals

supporting them about what they need and want as they move from childhood to adulthood. The findings are not therefore organised by ‘sector’ – health, social care, housing, education – because that’s not how people think about and experience their lives.

Instead, these findings are reported in the way that people described their lives to us –

- What are the most important things at this stage of life?
- How much do young people get involved in planning their own lives?
- What is family life like?
- What about friends?
- Who supports us?
- How do we get the support and services we need?
- What is good and not so good about the support and services we receive?
- What are my hopes for the future?

MOVING FROM CHILDHOOD TO ADULTHOOD – WHAT'S IMPORTANT?

Young people, parents and professionals had different ways of understanding the transition from childhood to adulthood. For young people it was about a life stage – leaving school and going to college, changes in your body, different relationships and starting work. Parents and professionals described it mainly in terms of which services end at age 16 or 18, and how young people can move on to adult services.

Young people's views about becoming an adult:

“There are physical changes that happen. You change mentally and realise that you don't want to be alone as an adult. Mood swings. Friendships change – they can become closer, or can change a lot and develop.”

“Getting a job, or your first experience of work. There is increased responsibility given to

you, which you have to earn. You are trusted increasingly with having money.”

When 91 young people ranked their priorities at this stage of life, choosing three from a list, ‘having friends’ was by far the most popular choice, followed by having enough money and understanding it, and being treated with respect.”

In contrast, parents and professionals' focus was on services, and what would be available after the move away from children's services and the education system. Although this concern is completely understandable, there is a risk that the social aspects of young people's priorities could be underplayed due to the focus on professional service delivery. The different priorities shows the importance of ensuring that children and young people's voices are taken into account. This is considered in the next section.

GETTING INVOLVED

Depending on a young person's needs, they may have different transition plans for education, care and support provided by Social Services, Education and Health.

The young people who told us about their experiences did not generally appear to be involved in transition planning and their voice does not appear to be present within planning and review processes, with a few notable exceptions. The exceptions demonstrate that young people can be involved in planning the support they receive, and that this is valued by them.

The general issue of involvement was highlighted in the evidence review:

‘A consistent comment throughout many papers relates to the ability of young people to be heard throughout the process. Commentators and researchers repeatedly articulated a concern that young people are still not being listened to and their preferences are not being acted upon.’

Young people's participation in transition plans

Researchers discussed transition plans with a total of 78 of the 99 young people and found that:

- **8 young people could describe their transition plan and their part in the process** of decision making. Example descriptions were:

“Social Workers come and go, but I know that the plan advises me about what things I might need. My parents will also be involved with it. We are waiting for a new Social Worker at the moment.”

“I had a plan for when I moved from children's services to adult services, but I am not sure what happened with it.”

“In transition from school to college, I was involved in it.”

“Everyone met with X and the family at the age of 13 years” [*supported by advocate*]

“She got to chair her transition plan meeting, had a say in it and it went better than she thought it would.” *[Explained by staff at young person’s request]*

- **53 young people did not think they had a transition plan** and that they had not been a part of the process of decision making in what they did after school. Within 3 fieldwork sites, staff intervened to correct the young people’s responses and told researchers “they have all been involved in transition planning.”

However, the young people did not appear to recognise the planning or their involvement and whilst some may have been involved from a staff viewpoint, it was very clear from the young people that the process had not been one which they felt they had participated within.

All of the 70 young people who felt they had not been involved in any transition plans understood transition planning to be in relation to moving to college and not in relation to planning any other services they receive.

Young people’s involvement in education

The researchers undertook activities that explored young people’s perceptions of their participation within **reviews of the support they needed in school**. Only 7 young people said they had been involved in reviews. For example, one young person said that she had been involved on a one to one basis and was involved in planning for the following year.

In four fieldwork sites staff said that young people were involved in reviews but in three of them said young people lost interest so were less involved, or that involvement was variable.

Our evidence review of other research studies found:

“The most important concern remains however why many young people are not included in the transition planning process and how this can be rectified. The planning process is time consuming, resource intensive and remains sector specific and poorly integrated across life domains. The question is why educational institutions continue to struggle with providing meaningfully inclusive practice

in this area and why holistic planning processes remain rare.”

Young person’s participation in their social care

With the exception of 16 young people living in one town in mid Wales, the majority of young people in this study who were engaged with social services did not feel that they participated within decisions about their social care or in social work reviews.

The consensus from young people was that social workers generally talk to parents and that they change jobs regularly. Only two young people mentioned participating in any social services transition meetings. Parents’ comments echo this lack of participation in social care:

“No participation in their own care at all.”

“The social worker has never had a conversation with my daughter.”

No young person mentioned having an independent advocate and parents also stated that there was “no mention of advocacy.” An advocate can help a child or young person have an independent voice in decisions. This can be particularly important when they have a different view to their parents or their parents don’t feel able to speak up on their behalf.

The Social Services and Well-being (Wales) Act 2014 gives a statutory entitlement to independent professional advocacy for all children in need of care and support. This Act also includes a presumption that any child with a disability is a child who will need care and support, under Section 21 (7). On this basis it is surprising that independent advocacy, offered through social services, has not been mentioned at all throughout this work and an indication that it may not be reaching those children who have an entitlement to statutory advocacy.



The data from professionals supports the apparent lack of involvement:

“Solutions should be child-centred. However, decisions are being made when decision makers haven’t even met the child.”

“There is a huge gap between what professionals think is person centred and what is.”

Additionally, some members of transition social services teams said: ‘... we don’t work with the children’ but instead described their role as one of coordination between child and adult services.

Participation and the Welsh Language

Families who use Welsh as their first language faced particular limitations in terms of participation since there appeared to be a lack of services available through the medium of Welsh. This issue was best summed up by a professional:

“No-one here has mentioned the Welsh Language, which really is the elephant in the room. Children and young people whose first language is Welsh are clearly being discriminated against, despite us saying equal status for the language etc. in some areas in Wales, there is no access to Welsh speaking services and in other areas where there are Welsh speaking staff there are no services at all. Welsh Government really needs to get a handle on this, as the issue doesn’t really even have any profile at all” *[Health Professional]*

Awareness of rights and equal opportunities

Approximately half of the fieldwork sites promoted awareness of rights with posters on the wall and some young people informed researchers about the UNCRC and how staff supported their rights to be implemented.

However, it was not apparent how rights-based approaches had been implemented into the transition process, even though rights based approaches were being implemented in other ways within the fieldwork sites. Young people who attended youth clubs, self-advocacy projects and transition projects were also aware of disabled people’s rights and appeared more able to articulate what this meant for them in everyday life:

“Don’t hold back or be ashamed of your disability.”

“Having learning difficulties is not your problem but society’s problem.”

“Having a learning difficulty is a part of you.”

Some parents also highlighted how their son or daughter needed to actively be given equal opportunities so that they could live an equitable life compared to non-disabled peers:

“Being valued as a citizen and human being would be the most important. Having the same opportunities as her peers, having a say and control over her life and for independence and development skills to continue.”

FAMILY LIFE

Parents of young people with learning disabilities have additional caring responsibilities compared to parents of non-disabled children, and those caring responsibilities do not diminish as the child grows older. Parents have to find the balance between enabling their child to become an adult whilst also continuing to support their care needs.

Because parents play such a crucial role in transition, this section explains some of the barriers they face, as well as young people's perspectives on their parents' role.

Not all parents reported difficulties. But approximately half of the total who used specialist health services and one third of those accessing statutory social care services described how difficult they found it to work with services; with many pointing to the problems of managing multiple appointments and different services.

Personal organising and administration

The following quotes exemplify the experience that many parents had in trying to coordinate services for their young people:

"The endless appointments have been a real pain and a source of great time investment for me...The paper based NHS is a big job for me in terms of managing the appointments."

"I have found that I need to be a secretary and administrator to the multidisciplinary team that my son is supposed to have. If I don't chase them up the appointments don't come and the assessments get missed and we've even been discharged for missing an appointment due to illness. A clerical error which cost me months of phone calls to reinstate. They never communicate between departments. They rarely turn up to meetings for reviews ...

we are inundated with organising all of the services constant involvement."

"I have to manage different health services - can be 5 or 6 different services. Managing paperwork which sometimes doesn't get passed between health services leading to endless repeating of medical history."

Additionally, most of these parents felt that their experience of supporting their young person was often ignored once the young person reaches adult services:

"Adult services do not recognise the parents' role and so you get shut out."

A few parents who did feel listened to wrote about this positively within questionnaires:

"They listen to what us parents have to say about the well-being of our child."

Section 19 of the Social Services and Well-being (Wales) Act 2014 is clear that wherever feasible any carer that the person has must be involved in any assessment of need (section 19), care planning and review (Section 54).

The dual feeling of organising a number of appointments and also being unheard during discussions within the appointments takes a toll upon parental emotional health. The data showed a consensus of parents describing unsupportive experiences as 'struggle' 'battle' 'stressful' and 'fearful' with a very small minority alluding to

suicidal thoughts and attempts with comments such as:

“You do get to see them if you try and end it all ... but it shouldn't have to get to that stage.”

It also adds to the fears and concerns that parents have for their young person as they become an adult, since adult services tended to involve parents less than children's services.

Parental concerns for their young person with a learning disability

Since parents coordinated most of the services that their young person used, transition to adulthood involves a fear that without the parent coordinating the services, the young person will not access them. This was accompanied by a fear that when the parents became too old to care for the young person no one would look after them:

“My biggest, darkest fear is dying and leaving him alone in the world. I don't trust anyone to look after him as well as I do...and there have been so many instances where society, where those who are supposed to support us have let us down.”

“If anything happened to us it doesn't bear thinking about to be honest.”

These deep fears and concerns placed pressure on parents and add to the emotional issues that they were already having to deal with on a daily basis.

Managing work and caring duties

A minority of parents described being forced to give up work for a variety of reasons which included:

- a lack of specialist or supportive child care;
- the amount of administration of appointments;
- managing temporary exclusions, or choosing to home educate (this was a small minority).

These issues were particularly a problem for single parents and women. Where parents had given up work, they experienced poverty and distress from trying to make ends meet.

“I can't work because no funding for specialist breakfast club or after school club.”

“I had to give up full time work because of school and health appointments for my son. Now I work part time a few hours to boost my carers' allowance.”

“Had to give up work to care for him during the summer holidays. (There's no care available for 19 year olds).”

Managing family life

Many parents felt they had to manage family life rather than just live it or experience it. Many parents described the strain of trying to meet other family duties and continue their caring role:

“I don't get to spend any time with other non-disabled children. Family life revolves around the disabled young person.”

“The whole family needs help and emotional support.”

Emotional impact of managing family life and a caring role

A minority of parents described how they were left alone to 'struggle' until crisis hit, which resulted in their young person entering residential care:

"Crisis hit and I'm now cut off from my child who has gone to residential setting."

"There's no help until a crisis comes and then our son went into residential which was a disaster."

Young people's views on the role of parents

All young people recognised that their parents found it difficult to reconcile the parenting role, caring role and support for independence. These views are summed up in these comments:

"They have your best interest at heart and each parent is a person too."

"Parents need help to let go and should know where to go to help you get advice. There should be more help for lone parents too."

About a third said their parents were overprotective.

Young people who felt 'overprotected' said they felt 'wrapped up in bubble wrap' and:

"[They] don't want us taking risks, but that is how we learn."

"I want to be a bit more independent. They stop me."

Young people who did not feel overprotected said:

"Parents nag you about your independence."

"I have freedom and my parents are looking after me."

"My Mum worries about me, but she cares about me, as I am only 17."

Additionally, one young person said:

"I actually need the help of parents and family, I have no choice."

Social care professionals echoed the sentiment that parents can be overprotective and do not support young people with learning difficulties to become independent:

"I have great difficulty with getting parents to realise their role in independent living and helping their children to develop self-care skills."
[Children's Disability Team Social Worker]

"But it's understandable that, and we need to provide parents with more support to be able to support their kids with becoming independent."
[Transitions Officer, in response to the above comment]

Professionals need to recognise the long-term emotional strain that many families will have been under, and that previous poor experiences of services may lead to mistrust and anxiety about whether their child's needs will be met.

It is also important to recognise that families will be crucial to the success of transition planning:

The literature also identifies families as a key facilitator for successful educational transition planning which can only work if parents and young people are kept in the loop, their social network is involved proactively, and where young people are heard and listened to in the process.



SUPPORT

In this section we explore who supports young people and their families during transition and what help they need. It is clear that young people see their greatest support by far as coming from their parents, with 77 out of 99 listing parents and families as supporting them. Nearly half listed school or college staff and others noted as supportive were careers staff, support staff, keyworkers, social workers, police and friends.

Encouragingly the vast majority of young people felt they had someone to help them:

“There's lots of help in school. A good Social Worker, who is helpful and is always in contact, so that I always know what's happening.”

Sadly a small number (9%) of respondents felt that there was no one who could give you good advice. Most of these were young people who had left foster care at aged 18 and felt alone, or who did not have a good relationship with their parents.

Whilst only a proportion of the respondents had access to a key worker or transition project, they were highly valued as a source of support and guidance:

“My key worker does everything.” (only 25 young people had access to key workers).

Support for parents

Parents, like the young people, get their greatest support from family members. This was the greatest source of support cited by parents (38%). Sadly the next most common response was ‘no one’ (32%). Less frequently mentioned were social workers, friends and school or college. Perhaps surprisingly, both health professionals and peer support groups were only rarely mentioned.

What do young people want help with?

Young people were very clear in the things that they need help with during transition.

- **Transport:** ‘The cost, confidence and tickets.’ ‘I need to know directions or have travel arrangements.’
- **Advice with studying:** ‘There are limited courses and you have to make choices’, ‘I find qualifications really difficult, the exams are hard.’
- **Finances:** ‘I am worried about money, paying bills and budgeting.’
- **Life skills and independence:** ‘Help with looking after yourself.’ ‘Doing your own housework and laundry.’ ‘Moving into supported living and how to do it.’ ‘Courage to go to new places.’
- **Work:** ‘Finding a job.’ ‘Help with filling in application forms.’
- **Managing friendships:** ‘Making new friends in college.’
- **Choices:** ‘Choices about how and who you trust, based on good advice.’

What would help parents more?

When asked: 'What help would you like?' parents identified the following:

- **Respite breaks.** Many parents said that they wanted respite breaks so that they could rest as they felt physically exhausted. Some parents also felt that respite should be used to further their young person's social skills and independent living skills.
- **Someone who will listen and give advice.** This varied between calls for 'anyone who would just listen' to 'guidance to get through the systems' through to 'explanations of education entitlements and opportunities.'
- **Better sources of information and flexible meeting times for working parents and lone parents.** Working lone parents particularly highlighted how difficult it was to manage everything. Suggestions included online leaflets and support via social media, evening and weekend carers' support activities, and online peer support.
- **Emotional support for parents.** Parents recognised that transition is a particularly emotional time and that they can gain help from each other but also need support for their emotional well-being.
- **Help with transport.** Some parents needed help to transport their child to school whilst others also said they need help with all transport because their young person could not use public transport.
- **Flexible support.** Some parents pointed out that there is no choice of services and that 'a one size fits all doesn't work'.

With the exception of support for transport, young people and parents are requesting help with somewhat different things. Young people expressed needing help with practical skills for adulthood (e.g. finances, managing work) whilst parents said they needed good information and emotional support. Effective transition planning that recognises the importance of family relationships could include the needs of the parents separately to the needs of the child; on the evidence that parents are an invaluable and primary source of support for the young people.

The literature also points to a largely underused resource in transition planning. Researchers note that existing social networks and family networks may function as considerable sources of support. This message aligns with increasing emphasis placed on asset based approaches in social care and should constitute part of any educational transition planning.

ACCESSING SERVICES

Most of the comments in this section come from parents and professionals, because parents are more likely to be trying to access services on the young person's behalf. It should be noted that there were many comments in parents' questionnaires that are not included here because they do not relate specifically to transition, but about which they expressed powerful feelings. This includes the difficulties in getting a diagnosis in order to unlock access to services, and access to mental health services. We will use this information in other policy and influencing work.

Accessing health services

Approximately one third of all parent respondents did not use specialist health services, so only two thirds of respondents had comments to make regarding health services and of these, half reported negative and frustrating experiences (i.e. one third of the total respondents). As is often the case within self-completed research, respondents did not particularly explain what was working well within health services.

When a young person is referred at transition age, health services can deliberate about which service the young person should be referred to, which delays both decisions and access:

"He was referred by a consultant (for OT) takes so long to access treatment. As he is 15 the health board spent 6 months "deciding" who should treat him adult services, the local children's centre or school physio ... eventually all they could offer was a session to show me what to do whilst we wait another 6 months for a free hydro pool slot."

Accessing health services can be hampered by residential placements. The comment below was a common experience for parents whose young people were in residential education placements:

"In 2015 CAMHS near school said he needed intervention, but would not provide it as he was at boarding school. When he came home it was the week after his 18th birthday and he came under adult services. It was a battle to get him seen, initially he was referred to the psychiatrist attached to the learning disability team, but did not meet the learning disability criteria. Eventually he was seen by a psychiatrist and referred to a psychologist who met with him weekly and stopped seeing him in order to provide support for support workers who have had no contact since."

The literature also identifies a specific subgroup of young people with learning disabilities which encounter specific difficulties in transition: young people living out of area. Their access to NHS and care services is fraught with particular challenges since they are often seen as only temporarily resident.



Access to further education

Access to further education varied according to whether the young person was accessing a mainstream or specialist course and the level of support the young person may need. 79% of all parent respondents reported having concerns about their child being able to continue to learn at college.

Parents who made additional comments regarding education tended to focus upon their children's needs and request specialist provision. They had high levels of concern about post school education after their child became 19 years old:

"There are no local colleges for people with severe disabilities. We are being pushed to residential. We don't want this."

"He will need an accessible college placement after he is 19. So far the only college we know of is over 100 miles away. Plus it's private and the funding will be difficult to get. Every agency will argue that they can't pay it. It's a very difficult road to getting what my son needs."

The lack of available choices meant some young people went to out of county placements and occasionally the lack of choice ended the young person's education:

"Left college now but had to go out of county to get needs met!"

"My son is now 19, he went to college but he was in a special unit and they had nothing for him to continue in the college after the special needs course finished."

"My son has severe autism and is non-verbal with challenging behaviours and where I live there is nowhere for him to go."

Changing thresholds between child and adult services

All three statutory services were described by parents to have different thresholds between children's services and adult services.

Generally, transition preparation greatly varies between different regions as well as between different services. For example, 8 parents from different areas discussed the age at which transition occurred within social care:

"You get dropped at 16,17,18" [*i.e. different ages from different respondents*]

"They withdraw at 14 to prepare you for adult services which aren't there."

However, for all services there was agreement that:

"You have to fit diagnosis and thresholds for adult services."

Thresholds were described to change on transition, with certain services only being accessible because of access to other services. For example, one parent explained this in relation to school and adult mental health services:

"[He] attended mainstream school. There is a lot of unnecessary criteria for adult mental health services as regards to whether your child went to a mainstream school the authority doesn't regard them as having a learning disability even though they have. This then removes the right for them to see the disability team, so you see the regular team who can't help them because they have autism!! So you see no one as has happened to my son."

"When the child finishes with paediatric services the care, support network and understanding goes with it. Adult services functions very differently seeing the patient more on an emergency rather than maintenance basis."

Some families found that they were 'signed off' prior to transition and therefore could not access adult services. Others found that services stopped at 18 and they had to apply for adult services:

"Respite stops at 18 and have to re-apply to adult services. It may or may not happen and will be a whole load of new workers."

The Social Services and Well-being (Wales) Act 2014 contains provisions that should by now be beginning to improve the transition between child and adult social services. This was not yet the experience of the majority of respondents to this

study. Similarly, the Additional Learning Needs and Education Tribunal (Wales) Act 2018 should, in the future, assist with the continuity of Individual Development Plans (IDPs) from leaving school age up to the age of 25.

Issues of access and delivery common to all statutory services

1. Access dictated by budgets

Parents felt that often 'decisions are budget-led' regarding service provision and are not based upon the needs of their young people. This was perceived to be the case regardless of the specific service:

"I want him to have as good an opportunity that he can and have opportunities for further education and learning. Our local council tries to dictate where my son should go and this of course is related to their budgets."

"Access to most health services i.e. physio, speech and language etc. have ceased due to budgetary constraints."

2. Inflexible service models

Professionals recognised that there were gaps for young people who did not meet certain thresholds or who did not fit specific criteria and explained it in terms of using inflexible models:

"We need to be asking what people actually need rather than what services are available."

"Services are inflexible, they ask people to 'meet' the service rather than the service meet their need."

Many parents and professionals discussed the lack of choice in services and how young people were "slotted into" existing provision rather than being able to have individualised services. An example comment regarding respite was:

"Respite is organised around the service not around the people in it."

3. Late decision making

Parents and professionals spoke about how late decision making caused worry and uncertainty even though planning took place over years:

"Late decision making and access to social care services. It definitely differs between areas. We have one Transition Plan Officer basically overseeing 200 Young people from two different teams." [Disabled children's team]

"We plan for 15 years old and upwards, but decisions are made late and this makes successful transitions difficult." [Education Staff]

"We had one Young Person who had a very last-minute decision of health care continuity lately, the day before we transitioned them." [Health Professional]

"My son is almost 19 and we have no funding agreements secured for his post 19 education. It's been a shambles since I started planning his transition aged 13."

The challenges of providing a smooth transition across a multitude of services is clearly evidenced in the research studies reviewed:

'The main challenge of transition remains to be one of different service structures between children and adult sector, different care approaches, different eligibility criteria and sectoral fragmentation in the adult provision. At the same time as young people experience biological changes, gain maturity and assertiveness, services in adult tertiary providers, such as mental health trusts, the NHS and local social services operate differently to those in the children's sector. This often leads to a delay in transition from children to adult sector altogether or a ceasing of service.'

"An important part of all successful transition planning is for young people and their families to be kept informed throughout the process and the literature highlights that many young people and their families are left in the dark about the future until very late in the day."

QUALITY OF SERVICE

Varied provision

Different regions and local authorities provide different services. For example, some authorities provided transition key workers (which are warmly welcomed by families), others have self and peer advocacy projects, whilst many appear to have neither of these provisions. Some local authorities have a focus upon support within mainstream schools whilst others do not. Some local authorities commission specialist youth clubs whilst others pay for individualised support packages without peer socialising opportunities. Our research also found that some areas have transition social workers and some have transition from children to adult services. Although some local authorities have recently moved towards all-age teams, none of the participants in this study had experience of them.

Preparation for independence

There was some criticism from both parents and professionals that mainstream schools are not focusing upon life skills that are needed for a successful transition to adulthood, and are instead focusing on core subjects and work readiness. However, some special schools were also seen to not prepare young people for adulthood in terms of core subjects, reading skills and life skills:

“While I appreciate the need for core subjects, without life skills, everything is a barrier in day to day life, when reaching transition to adulthood.”

“I am terrified for my daughter’s future. She has been completely let down by the education system. I am very realistic about her educational attainment. All I ever wanted was for her to learn life skills to help her live independently & have good self-esteem so she can be an active part of society.”

Some older young people felt they had been let down by education services during their transition and they listed key elements to being able to live independently that had been missing from their education. In common to all these elements was that the learning they did have was not related to practical everyday life and occurred too late in the education process.

Joint working

Parents and professionals identified similar areas for improvements to current joint working arrangements.

Communication

Professionals recognised that there was often poor or a lack of communication between services, and that information was not shared as necessary. Parents’ negative experiences were often underpinned by poor communication.

Poor coordination and decision making

Parents highlighted that although meetings and discussions about transition took place before a young person reached 18, no one coordinated transition and so decisions were delayed:

“There is no overarching support or expertise and parents are forced to act as go-betweens constantly. “

“I have been incredibly proactive in planning transition, but despite this the results coming through transition have been very poor, he is in the last year of education (one term to go) and we STILL don't have a provision for education or social support agreed.”

“Who makes decisions? It takes a lifetime to get agreement.”

Professionals also spoke about how poor planning and decision making was between services:

“I think the biggest difficulty in making services meet needs is the fact that there are just too many people involved to make effective decisions. Sometimes we literally don’t have enough chairs in the room, we’ve had 18 professionals in the room for one individual and not a decision is made.” *[Head Teacher of specialist provision]*

“I’ve sat in meetings with all of these different professions... (listed a few) and I’ve thought about how much each of their salaries are and how much of an expense this meeting actually is and not a decision was made. They all leave that meeting expecting someone else to make the decision.” *[Transition Social Worker]*

Parents experience these problems in, for example, not having care packages in place before care plans had been written and a lack of lead in to changes that occurred at 18 years old.

Commissioning and strategic planning

Professionals described some general problems with commissioning and planning for young people with learning disabilities:

“There’s a tension between the commissioning service and what’s available. What’s available may not suit needs and we need to focus on the support that’s best for their needs rather than moving forward without forward planning.” *[Social Worker]*

“Different monies being available for different bits of the problems means people aren’t working together.” *[Health Professional]*

“Whilst we have an autism strategy, there is no learning disability strategy and this causes confusion in strategic planning between the two areas of need, compromises strategic planning overall and creates pressure on learning disability services.” *[Health Professional]*

GOOD PRACTICE WITHIN SERVICES

Whilst the data clearly showed a number of problems, and the lack of national consistency posed additional obstacles for identifying good practice, there were pockets of good practice identified by young people, parents and professionals.

Professionals that coordinate

The data was clear that where young people have a key worker, whether through a voluntary sector project or statutory services, they felt confident about transition and had a named accessible person who can coordinate transition with the family:

“Having one key worker for the whole process is positive, even if the transition isn't 100% successful; having that continuity is positive and also extending the support past the age we do now.”

Where the voluntary sector took the lead or responsibility for key working or co-ordinating services, it was subject to changes in funding and tended to be short term, whereas where statutory services provided key working, not only did the voice of the key worker tend to have more authority but there was also more continuity in service provision.

In areas where there was not key working or transition projects, parents praised other professionals who took a coordinating role, which included teachers, GPs and paediatricians.

Professionals that work 'with the person'

There was no particular job role or sector that was specified within this approach. Parents and young people spoke highly of professionals and practitioners that worked with them and, whilst recognising the need for support, did not define the young person by their learning disability. It appeared that professionals that used this approach tended to be within front line delivery, but varied from 'mainstream medical staff' (e.g. A & E and dentists), some teachers, some youth workers, transition and key workers, and some social workers.

Transition and advocacy projects (including key workers)

Predominantly, but not exclusively, delivered by the voluntary sector, these were highly valued by professionals, parents and young people. Their success appeared to be knowing entitlements as well as local availability of services, having good rapport with a range of professionals, being coordinators for families, working with parents upon fears and concerns as well as with young people upon their practical priorities and flexibility.



FRIENDS, SOCIAL LIFE AND TRANSPORT

Young people identified making and maintaining new friends as their top priority during the transition process, and also identified 'managing friendships' as something they needed help with during transition. However, many have limited opportunities to have a social life outside of the family.

In addition to difficulties surrounding transport, the young people faced limited socialising opportunities due to other factors:

■ **Not knowing many young people in their neighbourhoods.** This was a particular issue for young people who attended segregated education (either in units in mainstream schools or specialist schools) because it meant that they did not know young people in their immediate vicinity or neighbourhood as friends from school were not within walking distance.

■ **Not attending mainstream youth clubs or using mainstream activities.** The vast majority of the young people did not attend any mainstream clubs or activities so their socialising opportunities were reliant upon segregated provision. Some of the young people only attended a specialist youth club once a month, but mostly they occurred once a week during term time. These clubs presented the only socialising opportunities that the young people had. It appeared that approximately 5 of the 99 young people attended mainstream leisure or socialising opportunities.

Participants spoke about socialising with their family during evenings, weekends and holidays, and parents, siblings and wider family played a significant role in providing socialising opportunities.

Overwhelmingly, parents reported concern about their young person's isolation as 83% of parent respondents replied 'yes' to the question 'Are you worried that your child may be socially isolated?' (i.e. 155 out of 187). 68% reported that their child never or rarely socialised or went out with anyone except family or paid staff.

Although some parents were pessimistic about their child's ability to make friends, or worried about bullying, others called for better support for inclusion and learning social skills:

"Emotional and social support for inclusion."

"My son wants to live a normal teenage life. He needs friends within his peer group."

Services that support socialising

Transitions and peer advocacy services described how they supported group members to keep in touch with each other by supporting them to use phones and keep contact lists, sending text reminders, and making plans with young people to extend their public transport use.

Specialist youth clubs were invaluable to young people for offering a space where young people could grow confidence, feel safe and meet peers. But they only offered one age limited opportunity rather than enabling social networks to grow. Some local authority areas do not support group activities but instead offer individuals a certain number of hours support to go out away from family. Whilst this offers a much needed break for families and ensure young people leave the house, they do not offer socialising activities or peer interaction.

A recent peer-led report by the DRILL project provides lots more information about the experiences of friendships and social isolation of young people with learning disabilities in Gwent.¹²

Impact of bullying and safety issues

Many parents stated they 'worry about bullying'. Young people also worried about bullying and some of them had experienced some extreme bullying:

"I was bullied at 16. They set fire to my jacket with me in it." (*Young woman aged over 21*)

Another young man explained how he had been bullied by the same young people since his childhood (he was over 21) and that this was continuing in adulthood. He had an app on his phone that sent an emergency text alert to all his contacts, so if he saw the people involved he could send an alert to everyone.

Many of the young people said that they were not allowed out in evenings because of parents' concerns about bullying. Four of the groups had had support from the police regarding cyber bullying and others had lessons in school and college about bullying. Two local authorities had a code word for the police so that if a young person with a learning disability contacted them with the code word the police know they may need additional support.

Impact of transport

Transport posed a massive barrier for young people with learning disabilities to see each other. They faced the same barriers as other young people in terms of cost and availability, but also faced additional barriers including accessibility, understandable information on times and routes, and support for travelling.

Transport is an issue at the transition for more than just socialising. Transport to college and work placements can be a barrier.

For parents who did not have access to a car or were at work, travel to and from school or college became a real cause for concern:

"We have been quoted £20 per day for taxi for college so 5 days a week will be £100. This comes to more than their benefit plus the other appointments we go to with them clubs etc. as they can't go out on their own."

"My son can't catch a bus but social services have stopped transport he can't cope he having melted down but he won't to carry on in college the taxis is going to cost us over 160 a week it will take all his PIP money."

Both transitions projects and self-advocacy projects supported young people with travel; often helping them to understand timetables and routes, working with local bus companies on disability awareness and accessibility, supporting young people to apply for a disabled person's bus pass and also providing travel buddies or lift share opportunities.

Young people in specialist settings learnt travel skills during years 12 to 14 and within college if undertaking independent living skills. However, most had not had support to travel prior to this, and had not been out alone, and therefore did not have much time available for progression.

HOPES FOR THE FUTURE

This final section of findings is about aspirations and hopes.

Aspirations and support for work

Work was the most important aspiration for young people.

The route to jobs was found to be fractured. No one (young people, parents or professionals) mentioned supported employment as a possibility. None of the young people spoke about apprenticeships or on the job learning and, anecdotally, researchers were told at fieldwork sites that most of the young people could not enter apprenticeships due to not having the entry requirements of GCSE Mathematics and English and colleges not providing part time apprenticeships. Work-based learning appeared to be a particular gap which contributed to the fracture between college options and work options.

Approximately half of the respondents had had work experience via their school in years 12 and 13 (aged over 17) but this was usually within specialist volunteer placements or in segregated environments rather than in the community.

There is also good evidence that work experience delivered in real life work environments is the most effective form of support for young people with learning disabilities. In addition, there are some signs that mentoring programmes help young people to cope with the demands of employment in the open labour market. In particular, peer mentors may be useful in this context as they shape young people and their families' expectations around work and having a job.

Stories were shared with us about young people not being paid for shifts, being put on long 'trial' periods with no pay only to find there was no job at the end of it or having additional hours allocated to them and then sacked when the pressure became too much:

"Employers give 'false hope', giving people hope and expectation that things will lead to a permanent job."

Some young people found that some courses of study and work placements did not allow them to get a full work or study experience. For example, one person was prevented from completing a motorcycle element of a motor vehicle maintenance course due to GCSE attainment in English (although he could complete the car maintenance modules without the GCSE attainment).

Parents also spoke about their aspirations for their young people to find work and focused upon the need to have decent 'social inclusion work opportunities'. Parents recognised the intrinsic value of work:

"He should have a job so he has worth and a something to get up for every morning."

"A job to give him routine and interests."

"A meaningful occupation and purpose in life."

However, parents were concerned about opportunities and discrimination:

"I worry he will be unable to keep a job due to lack of understanding of his condition by any boss and co-workers."



It is clear that many parents aspired to work or meaningful occupation for their son or daughter but were unable to see a way forward. Yet, the research evidence shows that families are key:

The strongest type of support which has shown to facilitate good employment outcomes for young people is families. Where parents early on identify employment as a viable and desirable option of post-education transition, a job or work placement with support is more likely to materialise. This points to the critical role families have in determining the transition outcome and how the transition planning needs to articulate and develop employment options sufficiently early for parents and young people to perceive it as a viable option.

There were a few stand-out examples of young people who had been able to pursue their very specific interests to improve quality of life or work opportunities:

- **a young person** who had attended Circus Eruption in Swansea for 5 years and was an adept performer upon certain circus equipment;
- **a young person** who was very interested in traditional blacksmithing and been able to pursue aspects of this; and
- **a young woman** who enjoyed needlecraft and sewing and wanted to set up a shop on Etsy¹³ to sell what she made.

The literature specifically mentions the critical role careers services play in transition planning and the evidence is not clear whether careers services meet their obligations of delivering meaningful career advice to young people with learning disabilities consistently. It appears that where careers services are proactively part of the transition planning and develop meaningful options for young people's post-school placements, transition outcomes improve and are seen as positive by young people and their families. Where careers services fail to be part of a person-centred planning process, their service is perceived as largely redundant.

28 out of 71 young people felt they had received advice about what to study in college. Not all the young people were asked the direct question because some participants were too old for

college and had left some years ago and others did not know if they were going to go to college or not.

Approximately 50 of all the young people had met with Careers Wales and talked about their future. There were a range of experiences of advice on what to study, with some reporting very positive experiences, and others feeling they had had little advice or support.

Overall, there appeared to be an expected route of school, to college, but then very few opportunities for work or meaningful occupation beyond this. The research evidence suggests that this is not aspirational enough for many young people with learning disabilities and that they can work, especially in supported employment.

There is also a clear consensus amongst researchers and observers that what works in employment for young people with learning disabilities is supported employment and that generic employment services are inadequate for this population. The lack of specialised support in this field for many young people with learning disabilities is a likely contributor to the high number of young people not in education, employment or training (NEET) in this population, most of them simply staying in the family home without any meaningful involvement in work related activities.

Transition to employment is thus well defined, well researched but also shows the least satisfactory outcomes. In contrast to all other transitions, such as health and post-school education, employment transitions are optional thus reducing pressure for services to develop this as a serious option for post-education day activity for young people with learning disabilities. The transition to employment also often takes place after the statutory transition planning process at an age where young people have grown into adulthood. Efforts to lengthen the planning process to the age of 25 (in Wales) should have an effect on this, but there has so far been no published evidence in the public domain.

Aspirations for hobbies, interests and having an active life

This area of life was the second most important aspiration expressed by young people and they talked about it in terms of 'having things to do' and 'living a full life'. Whilst it was mentioned as important by some practitioners with direct caring or learning support roles, other professionals did not mention the importance of meaningful things to do but instead spoke about 'provision' and 'packages'. Parents expressed this area of social life in the most aspirational terms, conveying a strong desire for their young people to just have 'a happy life.'

The top things that young people want to do in the future are:

- Travel
- Make new friends
- Do music and sports
- Have pets
- Socialise and have day trips

"Go and see the world"

"Hit the road with my friends"

"Learn to go out by myself"

"Meet up with friends more"

Conclusion

The experiences shared in this report highlight that young people with learning disabilities in Wales and their families continue to find the period of transition to adulthood fraught with anxiety and very difficult to navigate. Much of this could be eased by proper implementation of existing legislation that expects public sector providers to be citizen-centred. Transitions could be improved greatly by the straightforward and easily achievable steps of better involvement of young people and those who care for them, clear information, a shared approach to transition across agencies, and a keyworker to support young people and their families throughout.

More challenging but entirely achievable changes that would transform experiences would be integrated 'one stop' health and social care services that link closely with education providers. Greater social integration to tackle isolation should be the aim of the transition period and for the majority of young people with learning disabilities that should include real prospects for paid employment.

The recommendations that follow this conclusion fall into the following areas:

The involvement of young people in making plans for their future

I am particularly disappointed that despite current legislation, regulations and statutory guidance in social care, education and health, which states that children and young people should **be involved in planning and their views listened to**, the vast majority of young people did not feel this was the case. This was also the view of most parents and many professionals.

Young people involved in this report were not currently engaged with independent professional **advocacy** services and seemed unaware of their entitlements under the Social Services and Well-being (Wales) Act 2014.

Support for parents and carers

Parents and carers are central to young people with learning disabilities' support and care yet they often struggle to get the information and support they need. I feel that they need more support and recognition in their role and at the very least have clearer access to information about what support is available for themselves and their children and easier access to services they are entitled to.

A more coherent, joined up experience for young people and their families

Transitions are currently fractured and exceptionally difficult to navigate across different public services. Government guidance surrounding this is outdated and pre-dates the Social Services and Well-being Act and Well-being of Future Generations Act. Both of those Acts contain the principles and goals that should lead to a much better experience for young people at this stage of their lives and urgent action needs to be taken to make this a reality. Welsh Government needs to ensure that Regional Partnership Boards and Public Services Boards pay detailed attention to improving the experiences of young people with learning disabilities in transition to adulthood.

Better opportunities to be equal and active citizens

Children and young people with learning disabilities have the same rights as all other children to receive the education, care and support they need to fulfill their potential and to lead as full and active lives as possible.

It was striking to hear from young people and parents about how difficult it can be to develop and maintain friendships and social opportunities outside of the family, and how opportunities may narrow after full-time education is completed. Social opportunities will increase with employment, accessible transport and the preparation while in education to prepare for this.

Young people need to develop life skills while in education that will enable them to lead as full lives as possible. There are opportunities in the new curriculum to further develop this.

It was most disappointing to hear that young people and their parents appeared unaware of and lacking optimism in the prospects for supported employment opportunities. The Big Lottery is currently funding a large-scale 'Engage to Change' programme with Learning Disability Wales that should provide training and paid work opportunities for 1000 young people with learning disabilities and/or autism between 2016 and 2021. The Government has expressed a clear commitment under the 'Prosperity for All' programme to increase work participation by people with disabilities in Wales. It will be essential for the learning from the 'Engage to Change' programme to translate into lasting change.

What I will do as Commissioner:

- **My team and I will engage with** and monitor the 'Improving Lives' programme to support the change required for young people as they transition towards adulthood.
- **We will review the 2018-19 annual reports of the Regional Partnership Boards** to measure progress, identify positive practice in moving towards an integrated service experience for young people and their families, and highlight any remaining gaps and weaknesses.
- **We will continue to listen to young people and their families** about whether the 'Improving Lives' programme does indeed improve their experiences and prospects for living full lives as Welsh citizens.



RECOMMENDATIONS

The Welsh Government completed its 'Improving Lives' review in March 2018 with a paper that was presented to the Cabinet¹⁴. This review quite rightly placed an emphasis on the need for urgent, cross-governmental action to improve the lives of people with learning disabilities.

The Government has indicated that there will be an **'Improving Lives' programme** as a result of this which will link into the Government's wider 'Prosperity for All' programme, the implementation of the Additional Learning Needs Act and the recommendations of the Parliamentary Review into Health and Social Care.

This report brings detailed evidence to inform the 'Improving Lives' Programme.

I recommend that the programme has a distinct transitions work programme that aims to make substantial improvements to the experiences of young people as they make the transition to adulthood.

This work stream should ensure that Welsh Government and relevant public bodies make swift progress in delivering changes against the following areas within this Assembly term:

The involvement of young people in making plans for their future	Support for parents and carers
<ol style="list-style-type: none"> 1. The Welsh Government should issue updated guidance on multi-agency transition planning for young people with learning disabilities that includes a requirement to ensure that young people play an active and central role in planning for their transition to adulthood. 2. The Welsh Government should include specific reference to entitlements for young people with learning disabilities in the revised version of the Code of Practice for Part 10 of the Social Services and Well-being (Wales) Act, to ensure that children and young people are receiving clear information about and access to advocacy. 	<ol style="list-style-type: none"> 3. Every local authority should ensure that clear information about entitlements and availability of short breaks, carers' assessments and support, and transition arrangements is automatically and directly provided to families, as well as clearly located in one place on their own respective websites.
A more coherent, joined up experience for young people and their families	Better opportunities to be equal and active citizens
<ol style="list-style-type: none"> 4. The Welsh Government should issue updated guidance on multi-agency transition planning for young people with learning disabilities that includes a requirement for a lead keyworker to be identified for each young person and their family, one cross-organisational transitions plan and for local transition processes to be integrated across health, education and social services. 5. The formal evaluation of the Social Services and Well-being (Wales) Act will consider, amongst other things, 'what impact the legislation has had on individuals who receive care and support and carers who receive support'. Within this the Welsh Government should ensure that they are evaluating whether or not people receiving care and support as a child and as an adult are still experiencing a 'cliff edge' between services around the age of 18. This will need to be addressed if so, to realise the principles of the Act on person centred care and support. 6. The Welsh Government's 2018 review of concessionary transport schemes should consult with young people with learning disabilities directly, to provide services and schemes that meet their needs. 	<ol style="list-style-type: none"> 7. The Welsh Government should ensure that children and young people with learning disabilities are involved in the design of the new curriculum so that it meets their needs to live as full and independent lives as possible. Schools should be expected to provide opportunities for students with learning disabilities to form social relationships with non-disabled peers. 8. The Welsh Government should ensure that Regional Partnership Boards are making substantial and effective progress on the integration of services for people with learning disabilities, children with complex needs and transition services as required by the Social Services and Well-being (Wales) Act 2014: Part 9 Statutory Guidance (Partnership Arrangements). 9. The Welsh Government's 'Prosperity for All' Employability Programme should engage with and build on the learning from the current 5-year Big Lottery 'Engage to Change' programme in order to develop lasting and widespread supported employment opportunities for young people with learning disabilities who are able to take this up.

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This report is available in alternative formats on our website www.childcomwales.org.uk, by phoning us or emailing us on the details noted above.

FOOTNOTES

- ¹ Advice from a young person with learning disabilities to other young people.
- ² https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_summary-1.pdf?ga=2.124139593.2114276748.1527868820-1700713826.1504862745
- ³ <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>
- ⁴ <https://gov.wales/docs/dfm/minutescabinet/180306learningdisabilityimprovinglivesprogrammeen.pdf>
- ⁵ [http://www.assembly.wales/Laid%20Documents/PRI-LD9181-EM%20-%20Social%20Services%20and%20Well-being%20\(Wales\)%20Bill%20-%20Explanatory%20Memorandum-28012013-242600/pri-ld9181-em-e-English.pdf](http://www.assembly.wales/Laid%20Documents/PRI-LD9181-EM%20-%20Social%20Services%20and%20Well-being%20(Wales)%20Bill%20-%20Explanatory%20Memorandum-28012013-242600/pri-ld9181-em-e-English.pdf)
- ⁶ <https://www.gov.uk/guidance/equality-act-2010-guidance>
- ⁷ <https://www.equalityhumanrights.com/en/advice-and-guidance/public-sector-equality-duty>
- ⁸ Learning Disability – Improving Lives Programme, CAB(17-18)37, March 2018, page 1.
- ⁹ <https://gov.wales/docs/dhss/publications/180116reviewen.pdf>
- ¹⁰ <https://gov.wales/docs/strategies/170919-prosperity-for-all-enpdf>
- ¹¹ <https://gov.wales/docs/dfm/minutes/cabinet/180306learningdisabilityimprovinglivesprogrammeen.pdf>
- ¹² <http://www.carpcollaborations.org/images/DRILL-report-young-people-and-friendships-what-matters-to-us-1-1.pdf>
- ¹³ An online shop which allows members of the public and small businesses to sell their creative products
- ¹⁴ <https://gov.wales/docs/dfm/minutescabinet/180306learningdisabilityimprovinglivesprogrammeen.pdf>